DOCUMENT RESUME

ED 306 754 EC 212 818

AUTHOR Traustadottir, Rannveig
TITLE Women and Family Care: On the Gendered Nature of Caring.
INSTITUTION Syracuse Univ., NY. Center on Human Policy.
SPONS AGENCY National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.
PUB DATE Aug 88
GRANT G0085C3503
NOTE 24p.; Paper presented at the International Conference on Family Support (1st, Stockholm, Sweden, August 14-19, 1988).
PUB TYPE Speeches/Conference Papers (150) -- Viewpoints (120)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS Child Caregivers; *Child Rearing; Delivery Systems; *Disabilities; Family Life; Family Programs; *Family Relationship; *Females; Feminism; *Mothers; Parent Role; *Sex Role; Social Integration; Social Support Groups; Stereotypes

ABSTRACT

This paper challenges the traditional view that, in families of children with disabilities, mothers have the primary responsibility for child care because they are the "natural" caregivers. Family support services are an emerging way of delivering services to families of children with disabilities, and they seem to operate within a framework that accepts the traditional view of women as the "natural" caregivers. The rationale for family support programs focuses on the cost savings of providing care at home and the support of traditional family values. Caring, in its three identified forms (taking care of the child, caring about or loving the child, and caring about what happens to people with disabilities in general), is considered women's responsibility. Cultural stereotypes of men and women have significant influence on the way family support services are provided, and on the way that service providers view mothers and fathers of children with disabilities. The paper concludes that the disability rights movement and the women's movement may be in serious conflict, and that the disability field needs to develop a more sensitive perspective on women's issues to further efforts to achieve full community integration of people with disabilities. (JDD)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
☑ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

ED306754

WOMEN AND FAMILY CARE:

On the Gendered Nature of Caring (1)

Rannveig Traustadottir
Center on Human Policy
Syracuse University
724 Comstock Ave.
Syracuse, NY 13244
USA

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY
Rannveig Traustadottir
TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

Prepared for the First International Conference
on Family Support Related to Disability,
Stockholm, Sweden, August 1988

Preparation of this paper was supported in part by the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability Research and Rehabilitation under cooperative agreement no. G0085C3503 awarded to the Center on Human Policy, Division of Special Education and Rehabilitation, School of Education, Syracuse University. The opinions expressed herein are those of the author and no endorsement by the U.S. Department of Education should be inferred.

EC212814

ABSTRACT

Traditional studies of families who have children with disabilities living at home report that the mothers have the primary responsibility for caring for the child. This literature reflects the cultural stereotype of mothers as the "natural" caregivers and assumes that women's primary orientation is toward family and motherhood. This both reflects and constructs how we see, understand and interpret the lives of mothers of children with disabilities. This paper is based on a qualitative study of families who have children with disabilities and the services that provide support to these families. The study challenges the traditional view of families and tries to explore how stereotypical sex roles influence the caring for a child with a disability within the family. It also examines how traditional ideas and values about the roles of men and women influence the way family support services are provided.

The disability field is now in the midst of a period of reform. Part of this reform has been characterized by new ways of serving people with disabilities. The focus has been shifted from providing services within segregated residential institutions to providing services in the community. One of these new services is "family supports" for families of children with disabilities and there is now, for the first time, a clearly articulated intention to make a particular impact upon families. The goal of this effort (or "support" as it is usually called) is to encourage families to keep their children with disabilities at home. It should be emphasized here that I agree very much with the current reform efforts and see family support services as being of great importance. At the same time I worry about the lack of critical analysis of the impact of these new services on families. We are so convinced that family support services are good and important for families, that we don't question any aspect of these practices or the assumptions they are based on. Now is a good time to stand back and critically examine these new practices and how they are influencing people's lives, without being blinded by traditional and taken for granted views of the world.

Traditional studies of families of children with disabilities report that the mothers have the primary responsibility for caring for the child. (2) These studies have not seen this as an issue in need of further inquiry. Researchers have traditionally taken this

for granted and do not ask: "How come the mother is the primary caregiver and what does it mean for her?" Instead they assume that the mother is the "natural" caregiver and have not examined the sexual division of caring within the family.

During the past year I have studied families of children with disabilities and the services that provide support to these families. (3) In my studies I have challenged the traditional view of families and tried to explore how stereotypical sex roles influence the caring for a child with a disability within the family. I have also examined how traditional ideas and values about the roles of men and women influence the way family support services are provided. This perspective has allowed me to identify and examine issues that traditionally have remained out-of-sight. In this short presentation I can only touch briefly upon a few of these issues, but I hope the presentation will encourage people to look more closely and more critically at some of the new practices that now are being developed within the disability field. The research methods I have used in my studies are qualitative (4) and the presentation is based on:

1. A case study of one family support program.
2. In-depth interviews with families (both fathers and mothers) and service providers.
3. Participant observations in a parent support group and in training events for parents of children with disabilities.

TRADITIONAL STUDIES AND ATTITUDES TOWARD FAMILIES

Traditional studies of families who have children with disabilities living at home report that the mothers have the primary responsibility for caring for the child. This literature reflects the cultural stereotype of mothers as "natural" caregivers and assumes that women's primary orientation is toward family and motherhood. This both reflects and constructs how we see, understand and interpret the lives of mothers of children with disabilities. These studies are based on traditional ideas and values about the roles of mothers and fathers. These studies have not questioned that women are the primary caretakers of people with disabilities. When studying families researchers usually interview mothers. But when writing up the studies the authors most often refer to the "parents" views and experiences, even if their findings are mainly, or solely, based upon information from the mothers. One author, who reviewed the research literature on families, reports that "... mothers of handicapped persons were grossly over-represented in comparison to fathers." (5) This has at least two consequences. First, even if mothers are over-represented in research samples, the research reports hide the mothers and their experiences by constantly referring to "parents" or "families." Second, the under-representation of fathers leaves us without knowledge and understanding of the fathers' views and experiences. This under-

representation of fathers is so serious that the author quoted above suggests that "Much of the research leaves one wondering whether handicapped people have fathers." (6)

Today the social policy of community integration has become widely accepted within the disability field and many countries are developing a variety of services that have the goal of supporting people with disabilities in the community. Family support programs are one of these new ways of delivering services and there is now a growing consensus within the field that family supports are one of the essential parts of a new service delivery system. Without family supports it can be very difficult for families to keep their children with disabilities at home. At the same time there has been very little attempt to look critically at how family support services may influence the lives of the families, or the different influence these services may have on different members of the family. Most family support services seem to operate within a framework that accepts, almost unquestionably, and see as appropriate the traditional view of women as the "natural" caregivers.

TWO MAIN RATIONALES FOR FAMILY SUPPORTS

Families of children with disabilities have historically been faced with two options. Either to place their children out-of-home,

or take care of the child at home with little, or no, external assistance. (7) The third option, family supports, is now slowly emerging and there is a growing understanding and commitment to devote more attention and resources to support families to care for their children with disabilities at home. But because family support programs are a fairly new way of delivering services both authorities and service providers have to be convinced that family support is a better way of delivering services and more resources should be directed to develop new family support programs. When looking at the most common arguments used in favor of developing family support services there seem to be two main rationales that people use. First, an economical rationale. And second, an ideological rationale. (8)

The Economical Rationale

When researchers compare the cost of residential placements and the cost of home care, they find enormous savings when the care is provided at home. (9) Thus, one main argument in favor of providing family support services is that it saves money because it prevents costly out-of-home placements. In addition, adequate family supports may encourage families to take their children home from institutions and nursing homes.

The Ideological Rationale

As an ideological rationale people point out that besides being grounded in the ideology of normalization and community integration, family support services support traditional family values. Without

family support services families are much more likely to break up because of the additional stress it brings to the family to have a member with a disability. The goal of family support services is, by definition, to support the family as a unit, keep families intact and help families in their traditional role of "taking care of their own."

These two rationales have been widely accepted as two of the most powerful arguments in favor of family support services. (10) But a critical examination of these two rationales raises some concerns related to the underlying assumptions about the roles of mothers of children with disabilities. The first concern is related to the cost-savings of family supports: why do family support services save money? The most obvious answer is: because the mothers stay at home and provide the services at no public cost. Another concern relates to the idea of "traditional family values." Traditional family values bring to mind the culturally sanctified female role of caretaking and selfless giving. Traditional ideas and values about men's and women's roles within the family assign the responsibility for housework, child care and other caring work to women. Women have traditionally been expected to preform enormous amounts of unpaid work within the family. These traditional values also assume that women's primary orientation is toward family and motherhood. The reality today is that the majority of women work outside the home and are trying to negotiate their caring role within the family and work outside the home. (11) An uncritical emphasis on traditional family values as one major rationale for

family support services may lead to some serious dilemmas or conflicts and raises questions like: are we basing family support services on an outdated understanding of women's sex roles? Do present family support services assume and depend on substantial and consistent input of women's unpaid work in the home?

THE MEANING OF CARE

The concept of care is central to the way people talk about families of children with disabilities and how the families themselves talk. Caring is seen as women's responsibility and the mothers in my study all had the main responsibility for the caring for the child. Some of the fathers cared too, but the division of labor assigns far more responsibility for care to women than to men. Caring for a child with disabilities can be very hard work and some of the mothers talked about it as a burden. For others caring has been a source of deep satisfaction and pride, even if the caring has required the suppression of other capacities and desires.

Women's informal caring work has rarely been the center of focus within the disability field. The sexual division of caring has primarily been studied by feminist scholars who have shown a growing interest in what they most often refer to as "community care." While there has been some attempt within this scholarship to look at community care of people with disabilities, this literature has mainly focused on care for elderly people. (12) The sexual division

of caring for people with disabilities is largely an unstudied topic. Thus, at the same time caring is central to the way people talk about families of children with disabilities there have been very few attempts made to examine and understand caring in all its complexity. Most researchers use, and assume, a common sense understanding of caring; everyone "knows" what caring is and what it means. Therefore, they have not seen the need to explore the topic further. Because of this lack of inquiry into this central issue I decided to treat caring as a problematic topic and tried to rid myself of my own common sense understanding.

I listened carefully to what mothers, fathers and service providers said about caring, especially the mothers; they do most of the caring and should therefore be treated as expert witnesses. It was apparent that people talked about care in at least three different ways. First and the most common way of talking about caring was when people talked about caring for (or taking care of) the child. This meaning of care refers to the caring work. The second way of talking about caring was caring about the child, i.e., loving the child. These two meaning of care refer to how the parents (especially the mothers) relate to their own child. (13) The third way of talking about care goes beyond these personal relations to a broader community or societal concerns i.e., caring about what happens to people with disabilities in general and the way society as a whole treats them. I have chosen to call this third meaning of care "the extended caring role." (14) In the following section I will discuss briefly these three different meanings of care.

Caring For: The Work

The first and the most common way of talking about care was in terms of caring for the child. This way of talking about care refers to the caring work. This can be extremely hard and demanding work which often requires specific knowledge. Part of this work is the same kind of caring work that all mothers do when they care for their children. But when caring for a child with a disability the caring work often requires, in addition, specific knowledge and techniques that are usually associated with professional work, not housework or traditional "mothering-work." This is especially true when mothers are caring for children who are referred to as technically dependent or medically fragile.

Caring About: The Love

The second way of talking about care referred to relationships and emotions. The mothers talked about caring about i.e., loving their child with a disability. These two meanings of caring were often intertwined. Sometimes the mothers talked about the caring work and did not distinguish clearly between the love and the work. In other cases it was clear which meaning of care they were referring to. One of the things I found interesting when listening closely to the way people (mothers, fathers, and professionals) talked about caring was that the way people refer to caring for and caring about reflects that the mother is seen (both by herself and others) as the "natural" caregiver, both in terms of doing the work and giving the love.

Using the word care to refer to many and different things makes the whole discussion about caring confusing. This can also have some unfortunate consequences for mothers of children with disabilities. For example, if a mother thinks it is unfair that she has to take the main responsibility for caring for the child (doing the work) and wants others to share some of the work, it can easily be interpreted the way that she does not care about (love) the child. Not only can other people use this as a pressure on the mother to do the caring work, it can also create tremendous feelings of guilt within the mother, especially if she does not distinguish between these two different meanings of care.

The Extended Caring Role

What is probably unique about mothers of children with disabilities is their complex caring role. This caring role seems to work in at least two ways. On the one hand it can be extremely hard work that limits the mother in pursuing other roles and activities. On the other hand this role can be more flexible than the traditional mother role. If you have a child with a disability you are allowed to extend the caring role to activities that are much more like professional career-work than traditional mothering-work. One form of this extended caring role is when the mothers go beyond their own children and become advocates for change on behalf of people with disabilities in general. Many mothers of children with disabilities are active (some as leaders) in the parents' movement and spend much of their time advocating both on behalf of their own

child and on behalf of people with disabilities in general. In a way, these mothers set the agenda for other parents and lead, or help create, changes within the disability field. These mothers go to meetings, lobby the legislators, pressure the school boards, testify at public hearings, organize parents groups, and so on. These are activities that are usually not seen as traditional female activities, but when they are performed by mothers of children with disabilities, these are seen as an extension of the mother's caring role; an expression of the mother's devotion to her child and these activities are seen as benefiting the whole family. Thus, at the same time the caring role of women who have children with disabilities can be very limiting, this role can also provide women with opportunities that are much more like a professional career than traditional mothering-work. In a way, these mothers have made it into their career to be a mother of a child with disabilities.

TRADITIONAL VALUES:
HOW THEY INFLUENCE FAMILY SUPPORT SERVICES

Cultural stereotypes of men and women seem to have significant influence on the way family support services are provided and service providers seem to have different views and expectations of mothers and fathers. (15)

What the Mother Should Be Like

The mothers play a central role within the families in terms of doing the caring work for their children with disabilities. The mothers are also the main contact persons for the service providers. The mother usually initiates the first contact with the family support services and the professionals focus mainly on working with the mother. Family support programs seem to have a certain idea about what mothers of children with disabilities "should be like," and these ideas reflect the cultural stereotype of the selfless giving mother who devotes her life to the welfare of her child. If a mother does not live up to these expectations she risks being resented or rejected by the professionals. If the mother wants the services she can not deviate very far from what the professionals think she should be like, otherwise she risks being denied the services and that can be devastating for a mother who desperately needs the help from the family support program. If the mother does not live up to the professionals' expectations, they have a tendency to decide that the mother is unable to benefit from the services or that she is unfit to work with. If the mother deviates too much from what she should be like she may even risk having her child taken away from her. This creates a lot of pressure on the mothers to conform to the professionals' ideas of a traditional mother's role. This could be one of many complicated reasons why mothers of children with disabilities rarely reject the traditional role of the "natural" caregiver.

What the Father Is Like

Family support programs see the role of the father as being different from the mother's role and have different expectations of the fathers. The service providers, as well as the mothers and the fathers themselves, seem to have a similar view of what the father's role should be. The father's role is to be supportive of the mothers. Their role as supporters appears to be at least twofold. First, the father is supposed to support the family with adequate income and provide the economic resources needed to keep the child at home. Second, the father is supposed to be supportive of the mother's dedication and devotion to the child and her caring work around the child and the family.

The professionals also talk differently about fathers and mothers. When talking about the fathers they tend to describe what the father "is like." For example, if the father is involved with the child, participates in the caring work, has contact with, and cooperates with the professionals, they think that the father is exceptionally wonderful and praise him for being so involved with the child. But if the father is not involved with the child, has no contact with the service program and refuses to work with the professionals, then that is what the father is like, and the professionals say: "We cannot force the fathers."

Thus, the service providers see it as their role to have an impact on the mothers. They demand a certain level of cooperation and performance, and try to influence what the mother does and how she does things. At the same time they do not see themselves as having the same authority over the fathers and are very reluctant to put any serious demands on the fathers. This raises some legitimate concerns about the way family support services influence and control the lives of mothers of children with disabilities.

CONFLICTING INTERESTS?

Two of the most influential social movements after the 1950's are the disability rights movement and the women's movement. The disability rights movement demands full social and societal participation of people with disabilities and the women's movement has drawn attention to the unjust and inferior status of women and demanded greater equalities between the sexes. A critical examination of the current reform efforts within the disability field seems to suggest that there may be some serious conflicts between the interests of women and the interests of people with disabilities. Now is a critical time to explore to what extent the social policy of community integration may conflict with the political aim of greater equalities between the sexes. The disability field has not been aware of this possible conflict between disability issues and gender issues. It is essential that we

look more closely at these issues because I fear that if the disability field does not develop a perspective that is equally sensitive to the women's issues as the disability issues, the field may face serious dilemmas that can turn out to be damaging for the current reform efforts and attempts to pursue full community integration of people with disabilities.

FOOTNOTES

1) Sociologists usually distinguish between men and women in two ways. First, by referring to the sex of the person or the biological differences between women and men. Second, by referring to the gender of a person, which is the culturally and socially constructed differences between men and women. Many cross-cultural studies have shown that there is no general relationship across societies between social roles and biological sex. While all cultures ascribe different tasks to men and women, these tasks vary significantly between cultures. See for example, Ann Oakley (1972): Sex, Gender and Society. Melbourne: Sun Books. Margaret Mead's cross-cultural studies have also highlighted this issue. The title of this presentation refers to the "gendered" nature of caring. This reflects my belief that the different caring roles of women and men are socially and culturally determined or learned. I do not belief this difference is biologically determined.

2) The studies of families of children with disabilities which I have chosen to refer to as "traditional" are numerous. As a matter of fact, the overwhelming majority of studies of families of children with disabilities reviewed for my study took it for granted that the mother had the primary responsibility for the care and did not treat this as a problematic issue.

3) I would like to use this opportunity to thank members of the Center on Human Policy's research team for their on-going support of my research interest. These individuals are: Hank Bersani, Douglas Biklen, Robert Bogdan, Zana Lutfiyya, Julie Racino, Bonnie Shoultz, Steven Taylor and Pam Walker. I would also like to express my thanks to Sari Knopp Biklen and Marjorie DeVault for their valuable support and encouragement in developing the frame of analysis used this study. Last, but not least, I would like to thank Gunnar Dybwad for sharing his wisdom with me.

4) For information on qualitative research methods, see for example, Bogdan, R. and Biklen, S.K. (1982): Qualitative Research for Education. Boston: Allan and Bacon. Also, Glaser, B.G. and Strauss, A.L. (1967): The Discovery of Grounded Theory: Strategies for Qualitative Research. New York: Aldine Publishing Company. And, Taylor, S. and Bogdan, R. (1984): Introduction to Qualitative Research Methods. (Second edition) New York: John Wiley & Sons.

5) Wolfensberger, W. (1983): Normalization-Based Guidance, Education and Supports for Families of Handicapped People. Ontario: National Institute on Mental Retardation. Page 9.

6) Wolfensberger (1983) op. cit.

7) Much of the current literature on family support discusses this issue. See, for example, Agusta, J.M. and Bradley, V.J. (Eds.) (1985): Family Care for Persons with Developmental Disabilities: A Growing Commitment. Boston, MA: Human Service Research Institute.

8) See, for example, Taylor, S., Racino, J.A., Knoll, J.A., and Lutfiyya, Z. (1987): The Nonrestrictive Environment: on Community Integration for People with the Most Severe Disabilities. Syracuse, NY: Human Policy Press. Page 19.

9) The cost-savings of home care vs. residential placements are widely documented. See, for example, Bradley, V.J. (1988): The Medicaid Family and Community Quality Service Act: How Does it Address Research Findings, Quality Assurance, and Family Support? A statement prepared for the U.S. Senate Finance Committee, United State Senate, Washington, DC. March 22, 1988. And, the Governor's Planning Council on Developmental Disabilities (1987): Supporting Family Care of Persons who are Developmentally Disabled: Family Support/Cash Subsidy Programs. Springfield, Illinois: GPCDD.

10) These two rationales seem to be the ones most widely used in the United States. I do not know if this is also true for other countries.

11) Studies on the labor-force participation of U.S. women report that a clear majority of women are now working outside the home. See, for example, Fox, M.F. and Hesse-Biber, S. (1984): Women at Work. Mayfield Publishing Company. One study of working mothers in the U.S. reports that "... more than 52% of all women, married and unmarried, with preschool children are working." Berg, B.J. (1986): The Crisis of the Working Mother: Resolving the Conflict Between Family and Work. New York: Summit Books. Page 17. In some other countries women's labor-force participation is even higher. In Sweden, for example, in 1985, 80% of all women with children under the age of 7 were gainfully employed at least half-time. See, Child Care in Sweden. Fact Sheets on Sweden. Published by the Swedish Institute in April 1987.

12) Most of these studies on "community care" focus on caring for elderly people. See, for example, Ungerson, C. (1987): Policy is Personal: Sex, Gender and Informal Care. London: Travistock Publications. And, Waerness, K. (1987): "A Feminist Perspective on the New Ideology of "Community Care" for the Elderly." In Acta Sociologica, Journal of the Scandinavian Sociology Association. Vol. 30, No. 2. Other feminist scholars have tried to analyze the concept of care as it applies to all the groups who depend on others for their day-to-day care; including small children, elderly people and people with disabilities. These are for example, Finch, J. and Groves, D. (Eds.) (1983): A Labour of Love: Women, Work and Caring. London: Routledge and

Kegan Paul. And, Finch, J. (1984): "Community Care: Developing Non-Sexist Alternatives" in Critical Social Theory. No. 9, Spring 1984. The above mentioned feminist scholars are all either British or Scandinavian. Of North American researchers, Ann Bullock, Canada, is the only one I have come across who approaches "community care" similar to what I have done in my studies. See Bullock, S. (1985): Community Care: Ideology and Practice. A paper prepared for the Motherwork Workshop. October 4 - 6, 1985. Simone De Beauvoir Institute. Concordia University, Montreal.

13) In their examination of women's caring work, some feminist researchers have raised the question whether caring is "work" or "love" or a combination of both. See Marjorie DeVault (1987): "Doing Housework: Feeding and Family Life." In Gerstel, N. and Gross, H.E. (Eds.): Families and Work. Philadelphia: Temple University Press. Other feminist scholars who have dealt with the same question have come to the conclusion that caring demands both love and work and refer to caring as "a labor of love." See Graham, H. (1983): "Caring: A Labour of Love." In Finch, J. and Groves, D. (Eds.) A Labour of Love: Women, Work and Caring. London: Routledge & Kegan Paul.

14) Naming this "the extended caring role" reflects my attempt to make visible aspects of the complex caring roles of mothers of children with disabilities. The activities that compose "the extended caring role" are traditionally referred to as

"advocacy work." I think that seeing these activities as a part of the mother's caring role provides a better way of understanding the lives of mothers of children with disabilities and their complex caring role. This analysis is grounded in the way the mothers themselves talked about their lives. Many of the mothers described these activities, and the attitudes and feelings behind the activities, in terms of caring.

15) The analysis of how traditional ideas and values about the roles of women and men influence the way family support services are provided is primarily based on my case study of a family support program in Cincinnati, Ohio. At the same time I want to emphasize that this analysis seems to be true for other family support programs as well. Case studies of family support programs undertaken by other members of the Center on Human Policy's research team have highlighted similar issues. I have found two of these case studies to be especially helpful and inspiring for my analysis. These are: Bersani, H. (1986): Report on Calvert County ARC, Family Support Services. Center on Human Policy. Syracuse: NY. And, Biklen, D. (1988): In Support of Families: A Case Study of the Family Support Program of Macomb-Oakland, Michigan. Center on Human Policy. Syracuse: NY.